



Let's not go back to 'normal'! lessons from COVID-19 for professionals working in childhood disability

Peter L. Rosenbaum , Mindy Silva & Chantal Camden

To cite this article: Peter L. Rosenbaum , Mindy Silva & Chantal Camden (2020): Let's not go back to 'normal'! lessons from COVID-19 for professionals working in childhood disability, Disability and Rehabilitation, DOI: [10.1080/09638288.2020.1862925](https://doi.org/10.1080/09638288.2020.1862925)

To link to this article: <https://doi.org/10.1080/09638288.2020.1862925>



© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 23 Dec 2020.



Submit your article to this journal [↗](#)



View related articles [↗](#)




View Crossmark data [↗](#)

ORIGINAL ARTICLE



Let's not go back to 'normal'! lessons from COVID-19 for professionals working in childhood disability

Peter L. Rosenbaum^a , Mindy Silva^b  and Chantal Camden^c 

^aDepartment of Paediatrics, McMaster University, Hamilton, Canada; ^bOtago University, Otago, New Zealand; ^cSherbrooke University, CRCHUS, IUPLSSS, CanChild, Sherbrooke, Canada

ABSTRACT

Purpose: The worldwide COVID-19 pandemic has changed almost all aspects of our lives, and the field of childhood disability is no exception.

Methods: This article is based on an invited lecture by the first author at a conference—the eHealth Summit (“Pediatric Rehabilitation in a Digital Space”)—organized by the other authors and their colleagues in May 2020.

Results: The first author offers his own experiences and perspectives, supplemented by comments and observations contributed by many of the 9000+ attendees at this talk, as curated by the second and third authors. The basic messages are that while life for families of children with developmental disabilities, and for service providers who work with them, is significantly altered, many important lessons are being learned.

Conclusions: The comments from participants support the currency of the ideas that were presented, and encourage childhood disability professionals to reflect on what we are learning, so that we can seize the opportunities they afford to do things differently—and we believe better—moving forward.

ARTICLE HISTORY

Received 6 July 2020
Revised 5 December 2020
Accepted 8 December 2020

KEYWORDS

COVID-19 pandemic;
childhood disability;
pediatrics; rehabilitation;
telemedicine



► IMPLICATIONS FOR REHABILITATION

- Ideas generated by colleagues and parents suggest that there may be alternatives to “business as usual” in childhood disability services after the COVID pandemic is over.
- People are recognizing opportunities, and benefits, to offering services virtually, including being able to see children in their natural environments, saving parents time, money and hassles to attend clinics in person, and perhaps increasing the availability of services.
- Many issues remain to be investigated systematically, including, among others, what services (assessments and interventions) require hands-on connections, what payment structures can accommodate new models of services, how professionals can work together in a virtual world, and what families will want.
- Regardless of the final answers to these issues, we believe that we should not simply “go back to normal”; rather, we should expand the range, nature and locations of our services for children with developmental disabilities and their families.

Introduction and background

This article presents perspectives based on an invited talk that was part of a global effort to share ideas and experiences about childhood disability, occasioned by the COVID-19 pandemic. The talk (by the lead author) was delivered on 30 May 2020 and was offered during a 4-day eHealth Summit virtual workshop (“Pediatric Rehabilitation in a Digital Space”) created by a team led by the second and third authors (both academic developmental therapists) and many other contributors. The organizers had recognized that colleagues around the globe were facing, and struggling with, common challenges relating to the suddenly imposed transition to providing services through eHealth. (Information about this eHealth conference for pediatric therapists, and upcoming conferences, can be found here: <https://the->

[ehhealth-summit-for-therapists.heysummit.com/](https://the-ehhealth-summit-for-therapists.heysummit.com/)) (See also [1]. Overall, almost 10 000 participants from more than 16 countries participated, representing a wide range of professions and expertise. Attendees were predominantly occupational and physical therapists, but speech therapists, teachers, students and psychologists were also represented, followed by parents, medical practitioners, social workers and podiatrists. The 82 presenters (representing the aforementioned professionals and experts, including parents) delivered a mix of pre-recorded and live presentations, as well as interactive question and answer sessions hosted on Zoom, Facebook and Padlet. Padlet is a platform that facilitates online group collaboration where participants and speakers could interact asynchronously following the presentations. Participants were made aware, at the start of all presentations and via email, that live recordings and any comments they

CONTACT Peter L. Rosenbaum  rosenbau@mcmaster.ca  Department of Paediatrics, McMaster University, Canada Research Chair 2001-14, Co-founder, CanChild Centre, Hamilton, Ontario, Canada

© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

made on Padlet would be available publicly on the open web and might be used anonymously in future publications. Some of the comments posted on Padlet during the first author's talk have been used in this article *in italics* to illustrate participants' perspectives in response to the ideas shared during the presentation.

It is important to start with a statement of the obvious: the changes imposed by the COVID-19 pandemic have had a profound impact on everyone. We recognize a host of challenges to overcome, but also many opportunities to be seized. The COVID-19 pandemic has proffered a forced pause to our "business as usual", giving us a unique chance, rarely available in "normal" times, to stop, think, discuss, think some more, continue to discuss, and then make active decisions about how we move forward, and where "forward" might be. In ordinary times, we almost never have this chance—so for those, like the authors of this article, who work in childhood disability, we have a responsibility to engage in dialogue and active reflection. Three rhetorical questions were raised during the first author's talk, were discussed by participants, and are used to structure the present article: (i) How were we going about our "business" of "childhood disability" intervention in the "olden (pre-COVID-19) days"? (ii) How have the world-wide COVID-imposed "pause", and the myriad of changes in everything, impacted on (a) parents and families, and (b) service providers? (iii) What are we learning now that we believe should guide the "new dawn" of services—and how will we know we are doing better?

Context: Where are we coming from in "childhood disability", and where are we going?

How were we thinking about our field in the twentieth century?

Looking back, we can identify a number of important shifts in our thinking, many of which have happened imperceptibly [2]. We should recognize that our multi-disciplinary professional approaches to "childhood disability" were forged in twentieth century ideas, grounded in a faith that science would guide the way ahead. This had a pervasive influence on professionals, but was no less important for the public at large—including parents of the young people we meet professionally, the program managers of our services, the public, and the policy-makers whose thinking influences policies about children, disability, resource allocation and a myriad of other issues. The scientific era of health care appeared poised to address and solve the big issues in health and disease.

One of those traditional views focused on "fixing". Our biomedically-focused training emphasised "diagnosis" and "treatment"—ideas that were (and are) not wrong but simply, in our view, too narrowly considered. We expended considerable effort on diagnostic assessments, believing that "treatment" in early-onset developmental impairments such as cerebral palsy (CP), autism spectrum disorder (ASD), intellectual disabilities (ID), etc. needed to be diagnosis-specific (when in reality that is rarely true) [3]. The corollary of the hunt for a specific diagnosis was that interventions needed to be—and were—directed at improving the impairments in "body structure and function" (the biomedical problems underlying "disability"), with the assumption that children's capacities would improve as treatments "worked". Any successes of our therapeutic efforts were measured by rehabilitation professionals, looking at the goals we set and that organizations considered worthwhile. The work of Wright et al. [4] with children and youth with cerebral palsy receiving botulinum toxin for spasticity management explored these assumptions about treatment, and found them wanting. Their study showed that measured

changes in "impairments" (spasticity and lower limb range of motion after botulinum toxin use) did not translate into concomitant improvements in "activity" or "participation".

The authors are mindful of the reality that our service delivery systems in childhood disability are built on this somewhat dated way of thinking. Unless they are addressing "assessment" and "fixing" problems, many developmental therapists risk not being paid. This results in a significant focus on diagnostic labels, testing with standardised measures, and professionally-defined outcomes—driven and perpetuated by services that only are funded when these boxes are ticked—rather than focusing on modern ideas about health that strive to bring functioning to the fore in a useful way, as outlined below. This issue goes far beyond the specific ideas presented in this paper, but is identified here because it helps us to understand the mindset and context in which a focus on "fixing" remains so strong. It also helps explain the reality of the challenges that developmental therapists may face when asked to shift their focus to a more holistic approach to their work.

What's changing around us in the twenty first century?

- i. Our ideas about "HEALTH"
Health has been conceptualized as "the ability to adapt and self-manage in the face of social, physical and emotional challenges" [5]. In other words, functioning on one's own terms (however it is done, regardless of ability/normality) can be understood as evidence of health. This is a fundamentally different perspective than our traditional notion that child development should be marked by the achievement of a set of normative "milestones", and a belief that there is some standard of "normal" timing and quality of functioning. Huber *et al.* offer a refreshing alternative way of looking at "being" and "achieving"—one that hopefully liberates people whose development will always be different, but not necessarily "abnormal". (In fact, the idea of a binary choice of "normal" vs. "abnormal" is incredibly narrow, limiting and, in our view, inappropriate. Researchers have recently explored these ideas (for example, see Haque *et al.* [6].)
- ii. Our ideas about "DEVELOPMENTAL DISABILITY"
We are increasingly aware that early-onset developmental disabilities are not "diseases" requiring a "disease-treat-cure" system, but are conditions that refer to functional challenges (often impacting child and family development), and children's "being, becoming and belonging" (see Raphael *et al.* [7]). We use an "alphabet soup" of so-called "diagnoses"—CP for cerebral palsy, ASD for autism spectrum disorder, DCD for developmental coordination disorder, ID for intellectual disability and so on—for what are really descriptive labels (what has been referred to as "adjectives parading as nouns"). As but two examples: the word "autistic" was originally used by Asperger (see Sheffer [8]), and later by Kanner [9] as an adjectival description of the behaviour of a child who demonstrated certain social and self-referential behaviours; "cerebral palsy" was used to describe a CNS-based motor impairment and in fact mislabeled the problems as "palsy" (paralysis). Capitalizing these words makes them seem more real, and implies a level of specificity ("diagnosis") far beyond the realities of these "conditions". We understand that the diagnostic labels may provide a starting point for both clinicians and families, but unless the specific individual characteristics of the person and their functional abilities and needs are clearly identified, there is a

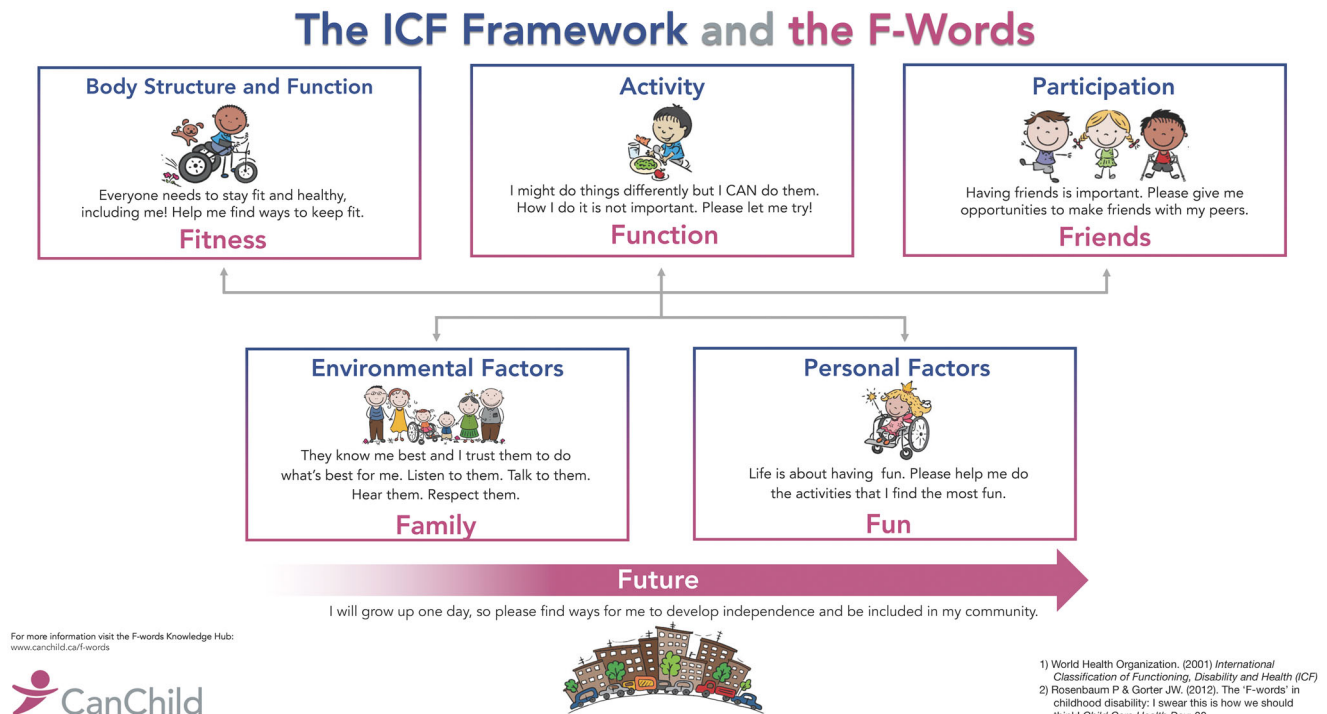


Figure 1.

risk that we will miss opportunities to tailor interventions to the person rather than the condition.

iii. *Moving beyond “fixing”: The WHO’s ICF and F-words...*

Key ideas that have been promoted in our field in the past decade are grounded in important twenty-first century thinking about “childhood disability”. One of the most significant conceptual advances, embraced by many of our colleagues, is the framework for health of the WHO’s International Classification of Functioning, Disability and Health (“ICF” [10]). This integrative biopsychosocial approach to health is comprised of several interconnected parts: health condition, impairments in body structures and functions, activities (and limitations thereof), participation (and restrictions thereof), and personal and environmental “contextual factors”. We like to think of this framework as a holistic “rule in” way of looking at children, families, and communities; it contrasts significantly from a reductive biomedical approach to “diagnosis and treatment”. The ICF’s “dynamic system” of interconnected parts reminds us that where we start our interventions may be less important than we used to think, because of the potential impact of everything on everything else. We particularly like the fact that the ICF reminds us to look at—and focus on—what people CAN DO! It offers a focus on child and family strengths! The whimsical “F-words” operationalization of the ICF concepts (function, family, fitness, fun, friendships and future—see Figure 1) has brought ICF ideas to life around the world, and has impacted parents, service providers, service programs and research activities [2]. (A host of additional materials and resources about the F-words are available for free at www.canchild.ca/f-words.)

The environment, which includes adaptive equipment and human help to support function, is an equally important component of the ICF framework. It reminds professionals to focus on the CAN versus the CAN’T and shifts the emphasis away from

ideas like “fixing”, and “disability” as solely a within-the-person affliction, toward a recognition of the essentially social implications of “disability”.

Ideas we need to *promote* include an emphasis on child and family development, child and family strengths, functional achievements (however they are done), being family-centred, listening to families’ voices, and addressing families’ goals. We need to recognize that “disability” is a social construct, involving factors external to the individual that impair their ability to perform to their best capacity. Note that this approach in no way diminishes the roles of professionals, or the importance of therapies. Rather, what it intends to do is to enhance the roles of parents and their voices, privilege parents’ values and goals, and see the child in the context of family and the many environments in which they live and function. The realities of childhood disabilities mirror those of other chronic conditions where health professionals should provide timely information and support, enabling the young person to take the lead in managing their own health (in the broader sense of the word) [11]. A change is needed in the dynamics of interactions between parents and professionals; empirical evidence suggests that families want to see this shift—and if they become unsure how to proceed, they can give professionals “permission” to guide them (see, for example, Holman and Lorig [11]).

How has the world-wide COVID-19 pandemic-imposed “pause” in everything had an impact on parents? Experiences, opinions and perspectives ...

Challenges

Parents and families of children with disabilities have clearly been significantly challenged by events beyond anyone’s control. Among the most obvious impacts are the limited availability of therapy and other services; limited connections with

others—including extended family, fellow parents, other support systems (such as “key workers” available in some countries); the exposure to a tsunami of materials, “resources”, opinions, advice of varying quality and relevance to their specific predicaments; and a host of uncertainties and discomforts imposed by confinement and added responsibilities.

On the plus side ...

When parents have had therapy sessions via Telehealth, they note the benefits of savings in time, effort, money and inconvenience that virtual appointments offer, unencumbered by travel, parking costs, waiting and coping with children who are often not at their best after car rides to clinics. They report increased ease of integrating therapy ideas into their everyday routines without having to “translate” what was done in clinic into their home environment, and they value the increased flexibility and availability that virtual visits make possible. In addition, parents have reported experiencing some surprising elements of respite from the relentless scheduling of their lives, with fewer appointments, and relief from the pressure to do “therapies” and follow management regimens. Parents have recognized that spending more time with their kids, while at times clearly stressful, has also led them to report (spontaneously) the FUN they are having with unstructured FAMILY time. Many have expressed genuine amazement at what they see their children learning and doing (FUNCTIONING) in “real life” situations—often things they had neither seen nor expected from their “disabled” children!

Following this talk, participants at the eHealth Summit, discussing the impact on families of the confinement and of using telehealth, offered the following *italicized observations and opinions*:

Challenges

- *Added responsibilities for families—wife, mother, therapist, teacher, worker. Potentially, Telehealth places even more responsibility and burden on the family. The same as parents have struggled to home school their children and were happy to send them back to school, many parents find that taking their kids to therapy relieves some of the burden on them so that they are in a position to support the therapy home programme but not BE the key therapists (OT, PT, SLT, etc.)*
- *Pressure on parents to “get it right”—cognisance around the impact stressors place on parent-child relationships—the parent is trying hard to cooperate with the therapist online, which puts a lot of pressure on them to have their child cooperate too and parents have reported getting frustrated with their child and then feeling guilty about this*
- *Inequities regarding software, hardware, internet access, literacy, tech support (for therapists and families)*
- *We don’t yet understand the impact on the therapeutic relationship when interactions are replaced by digital communication vs in-person interactions in the short and long term.*

Positives

- *So many parents ... and children need extra emotional support during this time. In addition, these times have been so helpful in helping parents to feel empowered.*
- *Some families have really appreciated the lock down, no stress with extra-curricular activities and time to refocus, reevaluate, and reconnect on what is important—and F-word Family has come out on top.*
- *Feeling more empowered to learn new ways to engage and help their child learn.*
- *Parents saying they have a better understanding of their child’s abilities.*

- *Huge benefit for opportunities to learn and integrate therapy into the lived experience of real life.*
- *Increased confidence with (parents’) own ability to implement ideas and strategies.*
- *Easy access [of eHealth]. Therapy is more real and transferable and more adaptable to family’s needs.*
- *Families report an improvement in their own skills and understanding of how to help their child, the pause has given them time to reflect on parent and child’s therapy goals. They find the therapy much more applicable and can hit the ground running—they don’t have the speed bump of transferring therapy ideas in the clinic to therapy ideas at home. Lots of reports of kids being more comfortable and responsive in the familiar environment of being at home.*
- *Obvious benefits of not having to travel to clinic appointments and manage childcare, etc. Other family members and siblings have been drawn into sessions and are learning how to implement ideas alongside the parents—truly helping integrate the therapy into family life.*

How has the world-wide COVID-19 pandemic-imposed “pause” in everything had an impact on service providers? Experiences, opinions and perspectives ...

We and our colleagues are all expressing serious concerns about the challenges faced by the families we serve. We are aware of the many ways that their lives are often already “complicated” by their child’s developmental and behavioural challenges. We know that many families may “manage” when things are relatively stable, but that the unpredictability of these strange times can create tipping points that produce huge emotional stressors and practical disruptions in families’ lives. We are only starting to learn about what we can do to be helpful in these COVID-19 pandemic circumstances of social distancing and enforced e-connections. In addition, for many professionals, children’s disabilities may take a back seat to their own more immediate and pressing health concerns, and impact their roles and their ability to earn a living. What might be the longer-term consequences of these issues on the pool of expertise needed by our communities to support children with disabilities and their families?

At the same time, just as parents are reporting some surprising insights, so we are also learning about a myriad of creative approaches by professionals to support parents and families. Being there—being available for telephone, e-mail or video-based connections—can be a source of significant reassurance, even when what we are able to do has constraints and is different from usual. Equally exciting are the creative ideas and insights emerging about how to assess children *in situ*. Many clinicians have not previously provided assessment and intervention in families’ homes, but with video-based visits we can see children in their natural environments and appreciate both the challenges and the opportunities afforded by those settings. And, like parents, we may experience revelations regarding children’s capacities that we had not appreciated when we saw those children in our environments. This in turn provides the opportunity to be creative when recommending ideas for interventions at home, using what’s available to families.

Examples of comments from participants at the eHealth Summit included:

Challenges

- *Inequities: software, hardware, internet access, literacy, training, tech support (for both therapists and families)*

- Lack of appreciation by funders of the complexity, time, expertise and effort required for Telehealth makes it potentially underfunded and unsupported by management.
- Legal and ethical obligations are not well defined.
- Privacy breaches are a concern.
- Information overload—knowing what is safe to use, what to use when, how to judge the quality and safety of an application, etc.
- Nobody likes being a beginner, particularly when there are so few guidelines and you have to learn on the fly (but everyone being in the same boat has made this more acceptable).

Positives

- Therapists have a greater understanding of difficulties that parents are having with the program and can adapt and advise in more applicable ways.
- Decrease carbon footprint.
- Can be more efficient and responsive.
- Can be more available in a way that suits families—“therapy on demand”.
- Less ability to jump in and “fix” means more time doing real coaching and problem solving with families—the therapist can’t just take over when things aren’t working (which we love to do!).
- A valuable tool in our toolbox—just another way to deliver services that when directed at the right family, in the right way, can be very effective.
- Easier to coordinate multi-disciplinary and trans-disciplinary approaches that fit with everyone’s schedules, including the ability to share information, videos, team goals etc.
- More insight into families’ lived experience, more able to integrate therapy suggestions into family home and lives.

What lessons can we learn and apply now, and in the future?

The first and most obvious question is: Should we aim to go back to “normal”? Our emphatic answer is: NO!

Let us start with the realization that “normal” wasn’t ever “normal”—it was simply “We’ve always done it this way”! We see no value in confounding “the usual” or “the way we used to do it” with the assumption that this was the best way, or the only way. In fact, what we have done in “normal” times, and how we have evolved our services and activities (because, as described earlier in this essay, they certainly have evolved and changed) usually happened incrementally, often with limited opportunities for reflection and review. Our systems are inherently conservative and making change is challenging.

Examples of comments from participants at the eHealth Summit illustrate these challenges:

- *I continue to struggle with systems change—we as individual therapists may be ready to change but the larger system doesn’t seem to be at the same place.*
- *There is more than one way to assess the child. Plus, the standardized tests currently in use, do these always give us helpful information? How functional are those T-scores? Are there other ways to gather information to better direct service delivery? Of course, but something will need to be changed from a systems level.*

Key messages

Based on this talk and the discussion it stimulated, we offer three Key Messages, including both the authors’ ideas and those shared by participants in discussion.

Key message 1: Don’t go back to “normal”!

We would invite therapists and clinical programs not to go back to “normal practice” as soon as they have a chance, but rather reflect carefully, ask parents what is most helpful to them, and explore how to incorporate these ideas into their (new) standard practices.

Let’s learn from these imposed changes, and apply the best of these lessons! Can we, for example, consider the **CONTENT** of our work? By content, we refer to our (professional) goals—what are we trying to achieve with our interventions—and to what we think families are looking for from us. We believe their experiences during the COVID-19 pandemic might influence us, just as our experiences influence us. The new practices experienced during the COVID-19 pandemic have forced us to use more collaborative practices, and design more accessible, responsive and supportive services.

Examples of comments from participants at the eHealth Summit, highlighting what therapists are hoping to change in the future, included:

- *I look forward to learning how to engage effectively in the next era of paediatric service to enable children to have happy functional lives.*
- *Telehealth is a window into the home and has helped me to understand the family dynamic more clearly.*
- *So important as the child functions within the dynamics of the family and community in their natural environments and daily routines, not just in a therapy gym with their therapist.*
- *I think telehealth is making me realize the importance of qualitative assessment to determine such areas as strength, motor coordination, and balance.*
- *We have been forced to walk our talk in coaching model and parent empowerment.*
- *Support, advice, confirmation that they are on the right track. Help with planning and implementing therapy, prioritizing and understanding what is really important vs what is “nice to do” and what is not. Problem solving and idea generation—partnership.*
- *Totally on board with the Fs, completely advocate for interventions using ICF—aiming at participation. I have worked for 15 years in (city, country) and my staff now have this in their DNA... participation for improved quality of life.*
- *The F-words don’t require our hands on the child. We have an opportunity to reset and rethink our approach, to focus on family and child strengths, coaching, and an approach that empowers families. Treating the whole person and not just the part! Holistic approach is what this view allows.*

Key message 2: Engage in collaborative goal-setting

We would invite therapists and clinical programs to seize the opportunity to engage in conversations with families about what would be meaningful rehabilitation goals. Today’s realities bring exciting opportunities to scale up collaborative practices, putting families in the driver’s seat, and ensuring support services are designed to foster engagement and be responsive to families’ needs.

This leads us to ask: can we reflect on and improve the **PROCESSES** by which we do our work? By process, we refer to the service delivery formats we use to interact with families. Now that so many of us have used eHealth, there is a growing realisation that much can be done without direct physical contact with children. Telehealth provides a tangible example of how we can both think and work. Telehealth actually provides an opportunity

Determining best fit for Telehealth vs In-Person sessions

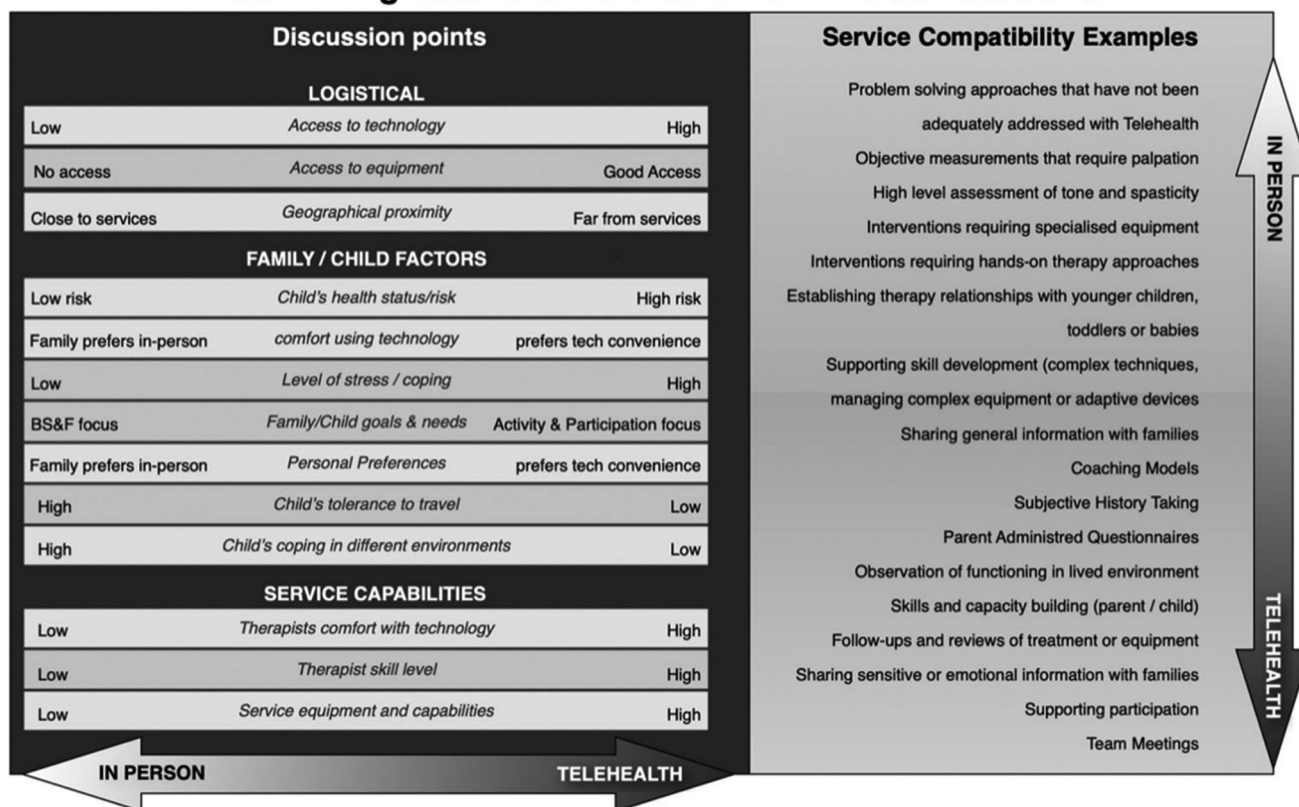


Figure 2. Reproduced from Camden and Silva [1], Pediatric telehealth: opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, <https://doi.org/10.1080/01942638.2020.1825032>, with the kind permission of the publishers.

to see the child in their real environment and shifts our focus to a broader view of functioning.

During the eHealth Summit, we asked therapists: What aspects of e-assessments and connections with families have “worked” (e.g., seeing people at home on their schedules)? What are the essential hands-on aspects of our work? Can we find the right mix of virtual and face-to-face (perhaps, in COVID-19 pandemic times, mask-to-mask) services? If we make the kinds of changes that we have been forced to adopt during the COVID-19 pandemic, what will be the markers of “success”– for families and for us as service providers–when there are more ways of providing services again?

Examples of comments from participants at the eHealth Summit, highlighting what therapists are hoping to change in the future, included:

- *A hybrid approach would be awesome, and asking families what they would prefer; I really appreciated the comment about asking families basic questions that may get overlooked*
- *Telehealth is a tool, a very effective tool to deliver high quality care. (Unfortunately in some cases it will depend on third party payers approval. At least in the US).*
- *I love the idea of combining the two to make a complete holistic program*
- *I appreciated the comments on how burdensome visits to the office can be and that we now might have the confidence to consider new models.*
- *I've been able to be more responsive–using multiple platforms, if Zoom didn't work, switch to facetime.*

- *My 14-year-old had a phone appointment this week–medication follow-up. Afterwards he looked at me and said “Why don't we always do it this way, it makes way more sense?”*
- *Perhaps a faster and more efficient connection even when face-to-face is possible. More flexibility for families and providers. Ability of parents to see therapy interventions in school when they can't physically be there.*

Key message 3: We can be more efficient and effective

Now that we have options, we should make sure we are offering families the most efficient and effective format for delivering services to meet their families' needs and goals. It is no longer appropriate to insist on a clinic or face-to-face visit without being clear about who benefits; nor will it be appropriate to insist on a virtual visit without the same considerations.

Can we strike a new balance with families regarding their competing needs and agendas? We encounter and work with families in the context of one specific aspect of their lives: they have a child with some kind of developmental challenge for which our advice and services are being sought. It goes (almost!) without saying that they also have a myriad of other realities to juggle. These include managing the costs of visits with us–costs that include, among many, time, money, inconvenience of travel, parking, waiting, possibly lost work and employment opportunities.

This leads to a key question: Can we learn from current (unstructured) observations and hints about the progress children are displaying when “therapy programs” are considered in the COVID-19 pandemic perspective? When we see progress despite

our inability to offer “service as usual”, can we pause and reflect on what DID work? When we are able once more to be together with these families and their children, can we use these observations to guide the focus of our interventions? What are we trying to achieve? What are families’ goals, and can we develop a shared agenda for our services?

It will not be a surprise to readers that the authors strongly believe that our focus, going forward, should be on child and family development, and on helping children to build on their best “capacity” so that everyday “performance” reflects those abilities. We believe that this is best done by building on an ICF/F-words approach to the “developmental” aspects of “developmental disability”, with full engagement with families. (As expressed by a participant in the Summit: *“I love the idea of focusing on family and child development rather than ‘rehabilitation’”*.) In considering where we might go when times allow in-person connection, we might want to reflect on what aspects of our work must be done in person, and what can be done in other ways (Figure 2).

Limitations

This paper presents the essence of an oral presentation, and a selection of the comments the talk generated at the time, on the issues brought to the fore by the COVID-19 pandemic. Participants at the conference were perhaps particularly proactive clinicians, and might represent a biased sample—yet we believe they expressed comments from clinical champions from our field from all around the world. This is not “research” in the usual sense, nor is it meant to argue that the ideas herein are necessarily generalizable. Rather, it is the authors’ intention to share a set of concepts in which we believe strongly, and a sample of the responses to these ideas. The precipitating event that led to the creation of the lecture series, of which this was the final, was of course the COVID-19 pandemic. Nonetheless, the basic argument is that this forced reconsideration of how we work in childhood disability provided an opportunity to reflect on what we are learning anecdotally, and how to apply the best of the lessons we have heard from families and colleagues. Finally, it must be acknowledged that this work dates from May 2020, and people’s realities many months later may be different now. Readers can judge that from their own current experience.

Conclusion

The purpose of this article was simply to offer some ideas that can be used to start a discussion about services in childhood disability. This is not intended as a prescriptive approach to our field. Rather, we hope that honest reflection of what we are seeing/hearing/experiencing will allow all of us—and families with whom these ideas should be shared—to look ahead rather than back. We have an unprecedented opportunity to apply whatever lessons we are learning and take advantage of the best of the COVID-19 pandemic-imposed changes in our field to make it even better!

Acknowledgments

In addition to MS and CC, who created the e-Health Summit, members of the development group included Michelle Wiley (physiotherapist), Shenadoah University; Christine Robenal (physiotherapist), Sweetpea Pediatric Wellness; Alison Hall (physiotherapist), My Kid Blooms; Deidre (Dee) Sperry (speech-language therapist), McMaster University; and Bernice Erikson (physiotherapist), <https://www.justbeconsulting.com>.

Disclosure statement

No potential conflict of interest was reported by the author(s).

ORCID

Peter L. Rosenbaum  <http://orcid.org/0000-0001-6751-5613>

Mindy Silva  <http://orcid.org/0000-0003-0404-5284>

Chantal Camden  <http://orcid.org/0000-0002-5503-3403>

References

- [1] Camden C, Silva M. Pediatric telehealth: opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities. *Phys Occup Ther Pediatr*. 2021;41(1):1–7.
- [2] Rosenbaum P, Gorter JW. The ‘F-words’ in childhood disability: I swear this is how we should think! *Child Care Health Dev*. 2012;38(4):457–463.
- [3] Rosenbaum P. Diagnosis in developmental disability: a perennial challenge, and a proposed middle ground. *Dev Med Child Neurol*. 2019;61(6):620.
- [4] Wright FV, Rosenbaum PL, Goldsmith CH, et al. How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? *Dev Med Child Neurol*. 2008;50(4):283–289.
- [5] Huber M, Knottnerus JA, Green L, et al. How should we define health? *BMJ*. 2011;343:d4163.
- [6] Haque OS, Lenfest Y, Peteet JR. From disability to human flourishing: how fourth wave psychotherapies can help to reimagine rehabilitation and medicine as a whole. *Disabil Rehabil*. 2020;42(11):1511–1517.
- [7] Raphael D, Brown I, Renwick R. Psychometric properties of the full and short versions of the quality of life instrument package: results from the Ontario province-wide study. *Int J Disabil Dev Educ*. 1999;46(2):157–168.
- [8] Sheffer E. Asperger’s children. The origins of autism in Nazi Vienna. London: W W Norton & Co; 2018.
- [9] Kanner L. Autistic disturbances of affective contact. *Nervous Child*. 1943;2:217–250.
- [10] World Health Organization. International classification of functioning, disability and health (ICF). Geneva (Switzerland): World Health Organization; 2001.
- [11] Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in care of chronic disease. *Public Health Rep*. 2004;119(3):239–243.